

Original Research

Illness understanding in children and adolescents with heart disease

ABSTRACT ● **Aims** To evaluate illness knowledge and understanding in children and adolescents with congenital and acquired heart disease and to assess whether the degree of understanding is related to age, sex, or complexity of the heart disease. ● **Design** Prospective cohort study. ● **Setting** Tertiary paediatric cardiac center. ● **Methods** Patients' understanding of their congenital heart disease was assessed in a representative sample of volunteers aged between 7 and 18 years using semistructured interviews based on Leventhal's illness representation model. ● **Results** Of 69 interviews, 63 were suitable for analysis. The number of boys and girls was similar, and they had a wide distribution of heart defects. Only 19 patients (30%) had a good understanding of their illness; 48 or 49 (78%) did not know the medical name of their condition, and 21 (33%) had a wrong or poor understanding of their illness. Understanding was unrelated to age, sex, or the nature of the heart disease. The understanding of illness duration was significantly related to age but not to sex or to the nature of the disease. ● **Conclusions** Illness understanding is poor in children and adolescents with heart disease, and many have an entirely wrong concept of their disease. Intensified efforts are needed to ensure better patient and parental understanding.

Accurate understanding of chronic illness in patients of any age is associated with less distress, less confusion, improved satisfaction with medical care, better compliance with treatment, and an improved emotional state,¹ all key factors for good health-related quality of life. In patients with chronic illnesses such as diabetes mellitus and asthma, illness knowledge has been poor.^{2,3} Some studies suggest that children with chronic illnesses do not know more about their condition or their body than their healthy counterparts.³ Traditionally, medical professionals have entrusted the parents of children with chronic illnesses with the task of imparting knowledge about the illness to their child. This practice assumes that parents understand the illness and that they pass on their knowledge in a manner appropriate for the individual child. However, parents often do not understand and may forget what they have been told.⁴

Some have argued that the emotional stress associated with chronic illness retards children's development.⁵ Patients may understand only part of what has been communicated to them, and wrongful understanding may persist or even be amplified with time. A lack of knowledge can lead to a general sense of confusion, heightened anxiety, and a lack of control.¹ In this study, we undertook a formal investigation of knowledge of chronic cardiac illness in children and their comprehension of the time line of their illness (when it started and how long it was likely to continue).

PATIENTS AND METHODS

Patients between the ages of 7 and 18 years with a wide spectrum of heart disease were identified from the Yorkshire Heart Centre, Leeds, England, congenital heart disease database and were invited by either letter or telephone

call, before a routine outpatient visit, to participate in an interview. Semistructured interviews were conducted based on Leventhal's illness representation model,⁶ which was developed to explore the beliefs children hold of their illness. Adolescents were interviewed separately without their parents, whereas the younger children were given the choice of having their parents present during the interview. Interviews were conducted in a quiet room decorated specifically for adolescents, and the interviewer was dressed informally. In the younger age group, the interviews were carried out in the home whenever possible. Free conversation was encouraged, using open-ended questions.

The following questions were asked: the medical name of their condition, what was wrong with their heart, how long they thought they had had the condition, how long they were likely to have the condition, and how their heart was likely to affect them in the future. The interviews were recorded and subsequently transcribed.

Standard methods of content analysis were applied to the transcribed interviews to provide categories for coding.⁶ A few (5%) of the transcripts were double-coded by a second evaluator to ensure coding reliability. High levels of rater agreement were achieved. Any differences in coding were resolved through discussion.

Knowledge related to the name of the diagnosis and ideas about what was wrong with the heart were assessed on a 3-point scale of wrong or poor explanation, partial explanation, and good explanation. The scale was constructed from identified criteria provided by the cardiologists.

Ethics approval was obtained from the United Leeds Teaching Hospitals ethics committee. Informed written consent was obtained from both parents and patients.

G R Veldtman
S L Matley
L Kendall
J Quirk
J L Gibbs
J M Parsons
J Hewison

Department of Paediatric
Cardiology
Yorkshire Heart Centre
Leeds General Infirmary
Great George St
Leeds LS1 3EX
UK

Correspondence to:
Dr Gibbs
jgibbs@cwcom.net

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Data analysis

We used χ^2 tests to assess whether the sex of the child affected illness understanding and the Fisher exact test to assess whether understanding was related to disease complexity. The Student *t* test was used to assess whether age was related to knowledge of the diagnosis name and whether an understanding of the time line of the illness was a function of age. Analysis of variance was used for comparing knowledge of illness and understanding of the time line at different ages.

RESULTS

Recruitment

Of 120 families contacted, 69 children and adolescents (58%) agreed to be interviewed. The recruitment rate was better with a personal telephone call (97%) than with a letter of invitation (44%). Data could not be used in 6 patients because of a combination of factors, including problems with recording quality, early termination of interviews as a result of previous transport arrangements, and interview technique. There were 30 boys and 33 girls, ranging in age from 7 to 18 years (median, 13 years). Their cardiac anomalies included isolated pulmonary stenosis, atrial septal defect, patent arterial duct, ventricular septal defect, tetralogy of Fallot, more complex cyanotic heart disease both with and without previous surgical treatment, acquired cardiomyopathy, and arrhythmias.

Illness understanding

Only 14 (22%) of the patients knew their diagnoses by name; 23 (36%) had a wrong or poor understanding of the nature of their cardiac abnormality, 21 (33%) had a partial understanding, and only 19 (30%) had a good understanding of their illness.

The following examples of answers fall into each of the categories of understanding:

- *Wrong or poor explanation:* A 13-year-old with mitral atresia, double-outlet right ventricle, and banded pulmonary artery who was awaiting cavopulmonary shunt operation: "I've got half a heart, and it's got a hole in it, and it's upside down."
- *Partial explanation:* A 14-year-old with pulmonary regurgitation related to previous surgery for right ventricular outflow obstruction who was awaiting homograft replacement of the pulmonary valve: "I know the valve leading to my heart is narrow, and there is leaking from it."
- *Good explanation:* A 17-year-old with repaired tetralogy of Fallot and complex arrhythmias: "When I was 3, I had heart surgery for a hole in my heart and narrowing of the arteries. They patched up the hole. As far as I know, I've been fine since. As far as I know, the artery isn't too wide and the 2 electrical centers are not coordinating properly."

After cardiac anomalies were categorized into simple defects that would not normally be associated with long-term morbidity or mortality (pulmonary stenosis, atrial septal defect, arterial duct, and small ventricular septal defect) and more complex anomalies with potential for late morbidity (aortic stenosis, tetralogy of Fallot, mitral valve disease, complex disease, and cardiomyopathy), there was no significant relation between level of understanding and the patient's age, sex, or complexity of disease. Understanding of the time line of the illness, however, improved with increasing age; the mean age of those with good understanding was 15 years, and the mean age of those with poor understanding was 10.5 years ($P < 0.001$).

DISCUSSION

The usual practice in cardiac centers is to explain a patient's heart disease and its short- and long-term implications in lay terms, often with the use of simple diagrams, at the time of the initial diagnosis. Repeated explanation is often given on subsequent consultations, but no formal assessment is made of the understanding of the information given. Semistructured interviews offer an informal and open forum for patients to express their beliefs regarding their health and allow the interviewer some quantitative assessment of the individual patient's understanding. Our interviews were conducted along the guidelines described by Leventhal and colleagues.⁷ These guidelines were used to describe how people as active agents interpret and represent the information they receive about health threats from outside sources and from their bodies and how their subsequent actions depend on their understanding of that information.

Less than a quarter of our patients knew their diagnosis by name. This lack of knowledge was not related to age, sex, or complexity of condition. About a third of the children had a good conceptual understanding of their condition, but a third had either a completely wrong or a poor understanding of their illness. The lack of knowledge about diagnosis could have important effects on a child's ability to relay essential information at times of medical emergency, when others are not available to provide this. A lack of understanding of the basic diagnosis could lead to dangerous assumptions being made about emergency intervention. As children grow older, expectations that they will play an increasing role in the management of their condition begin to be established. The concept of children taking increasing responsibility for their own care is undermined by the absence of their ability to relay a basic explanation of the diagnosis.

Understanding of the illness time line was related to age, reflecting conceptual and cognitive development as a function of age. Researchers have shown that some children have a good understanding of the future implications of their illness but found no clear pattern in age differences

in acquiring this knowledge base. The findings of the present study suggest that the older the children, the more developed were their ideas about the effects of the illness on their future. The difference appeared to be largely attributable to stages of cognitive development, rather than the tendency of adults to avoid discussing emotive future issues with the younger children. Even within families that took an open and frank approach to information about the condition, understanding of the illness time line still appeared to be related more to age than to issues of over-protection or lack of discussion.

There are multiple reasons for poor illness knowledge in young patients with chronic disease. Although we did not specifically aim to identify these in our study, some of the factors have been previously elucidated.¹ Poor understanding of normal anatomy and physiology in both parents and the patients may be an important factor making subsequent comprehension of illness difficult. Inadvertent use of jargon and overly technical explanations of anatomy or physiology by specialists are likely to compromise effective transfer of knowledge. Patients forget a large portion of what they are told about their illness, even of those aspects that they originally understood,⁴ and over many years a patient's inaccurate concepts may be magnified. In patients with congenital heart disease, subtle developmental delay may also contribute to poor knowledge.⁸

Before this study, we thought that our policy for providing information to patients and their parents was adequate, but the study shows that our patients' understanding of their disease is limited. Counseling families on congenital heart disease can be time-consuming and assessment of the effectiveness of counseling even more so. There is good evidence to suggest that quality of life in terms of minimal anxiety, "coping" with disease, satisfac-

tion with treatment, and frequency of hospital admission in chronic illness is enhanced by good understanding of the condition. These aspects of quality of life for patients with congenital heart disease undoubtedly can be improved by intensified audited efforts to ensure better understanding. Such a process is likely to have important resource implications for centers dealing with congenital heart disease. The results of the study must also be considered with regard to the wider issues of children's and adolescent's rights to information, their increasing involvement in decision making, and their consent to treatment.⁹

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